

Demedicalization of Disability

a perspective from
persons disabled by environmental sensitivities

presented to the
Liberal Task Force
on
Disability Issues

Chris Brown
President, Ottawa Branch
Allergy and Environmental Health Association

Orléans
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Thanks

One of the first people on Parliament Hill to help us, back in 1987, was Liberal MP Sheila Copps. Among other things, Ms Copps has asked the government to help people who've been hurt by discriminatory attitudes fostered by the very people who should have helped us.

The former Minister of the Environment, Charles Caccia, has also been very helpful. He recently secured a statement from Health and Welfare that, in ambiguous cases, sensitivities should be ruled out before a psychiatric workup is done. He has asked the department a number of times to help rescue those psychiatric patients whose central nervous system dysfunction is caused by undiagnosed sensitivities.

There are a couple of members' assistants, particularly Gord Douglas and Glen Okranitz, who deserve thanks as well. It's hard to express how much their help has been appreciated. The memory of the desperation and very real terror many of us have felt, that many of us still feel sometimes today, can be overwhelming, despite some improvements.

Dr. Bruce Halliday, a conservative MP, has been a prince. Although he's a doctor himself, he has pressed hard to demedicalize the government's approach to this

disability, in part by helping to make sure that the recent Health and Welfare workshop and report dealt with social, self-help, and educational concerns, in addition to science and the medical arts.

You will be familiar with his work as Chairman of the Parliamentary Standing Committee on Human Rights and the Disabled. You will know that the work of that committee has received only lip service from the government, and that he and the rest of the committee have asked the government for some indication of what they intend to do about disability issues Canadians have said they want dealt with.

I hope that your Task Force will complement and support his work, and that of the Parliamentary Committee. Dr. Halliday deserves some kind of parliamentary award.

I'd like finally to thank two members of the cross-disability movement, Charles Sheppey and John Lane. I first met them in the mid-seventies, when they were organizing physically disabled consumers to win access to public buildings and community services, something the environmentally sensitive are just starting out on.

They achieved accessibility in Ottawa, as far as it's gone, with lower telephones and elevator buttons, wider doors, dips in the sidewalk for wheeled vehicles, and so on. But, of course, they achieved far more. Through STAND, the Society for the Aims and Needs of the Disabled, they brought hope to physically disabled persons, the strongest form of hope there is.

They created a sense of hope that was based on people's worth to themselves, on our ability to act, to maintain control over our own lives, to escape from the smothering effect of being looked after by experts who are too often presumed to know more than we do about what we need, and even what we want.

Emergence

Environmental Sensitivity is an umbrella term referring to a compendium of disorders. Persons with sensitivities react at levels of exposure to natural and synthetic chemicals that don't seem to affect the majority. Any system of the body can be affected, from mild discomfort to total disability.

The Thomson Report, in Ontario, lists symptoms affecting every organ system of the body, including

respiratory effects, birth defects, immune dysfunction, and even central nervous system dysfunction.

Although we are made more disabled by polluters, this is not a new illness. Contrary to public impression, the problem dates back generations, and medical literature to before the turn of the century.

Our progress has been helped by scientific reports, but more by those who have spoken out on human rights and social concerns related to this disability.

In 1985 a report commissioned by the Ontario government decried the "acrimonious debate" over environmental sensitivities, saying it was "eroding confidence in the health care system". The authors called for "collaborative efforts to help a growing number of patients", stating that it was "clearly untenable" to say the problem was 'all in the mind'. The president of our association at the time indicated people were committing suicide because doctors were telling them they were crackers for thinking they were affected by the environment.

In 1989, a report to the New Jersey State Department of Health made similar observations, and strongly recommended checking for sensitivities before embarking on "potentially detrimental" psychiatric

interventions. The New Jersey State Department of Health was presented an award for their work by the World Health Organization.

And a couple of weeks ago, Health and Welfare released a special issue of "Chronic Diseases in Canada", dedicated to environmental sensitivities. It's about a workshop organized by the Laboratory Centre for Disease Control a year ago. Participants included representatives from the Canadian Medical Association, several provincial Ministries of Health, specialists in various areas of medicine, and consumer groups representing people affected.

The report lists several recommended means of testing people with sensitivities to see if substances they are sensitive to are affecting them. It indicates that some sensitivities may not show up in tests. It recommends that insurance companies be prevented from discriminating against people whose sensitivities cause disability.

The report is being well received. It has been distributed to thousands of doctors, housing and disability departments, human rights commissions, and other sectors of the health and social services communities. A recent headline proclaimed the "Report urges respect for environmentally sensitive".

This Health and Welfare report is the latest in a long line of reports in various jurisdictions to point out that persons disabled by environmental sensitivities are being caught in a medical debate about physiology, while simple, obvious, and needed measures to help are not being implemented.

Demedicalization of Disability

Journalists are sometimes criticized for "objectifying" people in their stories. It usually happens when people's ability to speak for themselves is superseded, when experts are thought to know more about the needs of a group than the people themselves. Human beings hear of themselves being discussed in the third person, sympathetically, and with good intention. Their only involvement in the story is to exemplify the theory or recommendations of a professional expert.

Unfortunately, as others have pointed out, sometimes this objectification disenfranchises. When people lose control over the expression of their own concerns, they lose control over their lives.

Objectification neuters people's ability to defend themselves against the kind of horrible abuse that, except for the grace of God, any of us may be subjected

to. Then, professionals, by acting dispassionately, may exacerbate the situation by sanitizing real horrors. People may be worse off if the professional downplays extreme violence, for instance, with dispassionate euphemistic jargon, or by describing an unreasonable situation in reasonable terms.

Peter Truman has written about this sanitization of issues in the media. He points out that journalists like professionals. They're articulate. They seem to know what they're talking about. Even when speaking out on issues, they have the semi-detached attitude journalists so strongly identify with.

But sometimes it seems that journalists use professionals to reinforce the myth of objectivity, to dull or escape their own community involvement and personal responsibility. (Cue brilliant, articulate, well-rationalized protest.)

As many of you will know, there have been extreme damages caused to persons disabled by environmental sensitivities. We were dismissed as neurotic, or malingerers. It was stated, publicly, loudly, and from persons with responsibility and authority, that people claiming to have this problem didn't know when they knew something and when they did not.

We were sometimes portrayed as possibly trying to pull something off, trying to sucker the good will of others, perhaps the sleaziest of human transgressions.

We were objectified, reduced to the role of supposedly exemplifying the latest medical theory or method. Worst of all, we were not given credence to speak for ourselves, to describe our own needs.

The effect, as you know, was not simply a lack of appropriate medical care. Being objectified made it extremely difficult to fight back against millions of dollars damages, increased disability, personal tragedy, and even deaths.

It should be emphasized that this suffering occurred, not because we're disabled, but because our dignity was not respected. Our experience as human beings, as citizens in a democracy, was dismissed (objectified) unethically, not on the basis of information, but on the basis of an absence of any physiological understanding of what was happening. Meanwhile, most persons with sensitivities were as aware of their reactions as plainly and as obviously as if someone was standing on your foot, or if you burned your hand on the stove.

It's bad enough to experience an assault by polluters, and to have no real defense. Imagine the horror parents feel, watching this and other abuse explained away dispassionately, seeing no one in authority stop it. Seeing no action against the abuse parallels the experience of survivors and victims of Mount Cashel, only on a much bigger scale. Denial and sanitization sustain the horror.

Imagine the sense of powerlessness of parents whose kids are being abused by school boards, even right here in Canada's Capital. Macho games at the Carleton Board of Education, for instance, sustain the continued abuse of little children in their care.

Objectification of the environmentally sensitive has left us vulnerable to a kind of inadvertent terrorism. If we had been left our dignity, if we had been taken in good faith until proven otherwise, this wouldn't be happening. We wouldn't have been put in a position of guilty until proven innocent, our reputations called into question without reason. We might not be faced with self-important professionals who have dug in their heels, some of whom seem to be sustaining the abuse simply to protect their reputations.

Without objectification, there would more likely be supportive and co-operative attitudes in the community, although certainly attitudes are already improving.

But the history of the environmentally sensitive is an excellent argument for the demedicalization of disability. Persons with disabilities want to speak for themselves, to tell their own story. It is a violence when they're not allowed to, in our case very horrible violence.

Recommendations

1) If you were to ask me what the environmentally sensitive need more than anything, I would answer "each other". Health and Welfare, in their recent report, urges a number of self-help and public education initiatives by the largest self-help group in the country, the Allergy and Environmental Health Association. I urge you to support the provision of Health and Welfare sustaining grants to this organization.

2) The biggest job facing us in the Ottawa Branch of AEHA, is helping people come out from under the effects of abusive attitudes and violation by

authorities. I urge your support for post-traumatic counselling for persons with sensitivities and other assistance for people who suffered damages because of attitudes fostered by officialdom. I urge you to suggest ways of protecting others from similar future abuse.

3) Although Health and Welfare should be congratulated for a good beginning, continued efforts are needed to address misconceptions throughout the federal government and in the community. I urge you to call for the distribution of the LCDC report to management and line staff in relevant federal departments and agencies, and for continued efforts to address related concerns in various departments.

4) Because of negative attitudes that were fostered for so long, there is considerable evidence that many who have sensitivities have not been diagnosed. I urge you to support the rescue of those who remain undiagnosed especially those with central nervous system dysfunction which may be caused or significantly exacerbated by undiagnosed sensitivities.

5) Finally, I believe it is important to all persons with disabilities that the committee find

a means of making public a positive, unqualified statement of support for the demedicalization of disability, as advocated by the cross-disability movement.

Addendum

For all the millions of dollars damages, the pain of persons with sensitivities, even after all this there is something that may be more important - what all this means for other Canadians. The cost of our dignity being trashed may be far more for the community at large than for those who have the problem.

As former Ontario Environment Minister Jim Bradley said in a speech to our organization in 1987, "the environmentally sensitive are the first to feel the effects of pollution". We are like the birch trees, the first in the forest to be affected by acid rain.

Of course, we're different than the birch trees, in that we experience consciously some effects of pollution and we are able to relate our direct awareness to the "rest of the trees in the forest".

If people had been listening to us when we sounded the alarm a quarter century ago, perhaps we wouldn't be